

United States Senate

For Immediate Release

Wednesday, Sept. 10, 2003

Grassley, Kennedy Bill to Help Disabled Children Wins Committee Passage

WASHINGTON -- Senator Chuck Grassley, chairman of the Committee on Finance, and Senator Edward Kennedy, ranking member of the Committee on Health, Education, Labor and Pensions, today won Finance Committee passage of their bipartisan legislation to help disabled children.

“Medicaid works well for a lot of people,” Grassley said. “The problem is some families fall through the cracks. Many parents of disabled children have to drop out of the workforce or keep themselves in a low-paying job just to remain eligible for Medicaid. In effect, the government is forcing parents to choose between near-poverty and their children’s health care. We need to fix that.”

Kennedy said, “Parents of disabled children struggle every day to help their children to live independently and become contributing members of their communities. These families should not be trapped in poverty and denied access to the health care their children need. It is time to close this health care gap for the nation’s most vulnerable population, and enable families of disabled children in this country to be equal partners in the American dream.”

The Finance Committee on a voice vote passed the Family Opportunity Act, which has attracted widespread bipartisan support in each Congress since the senators authored it in 1999.

The Family Opportunity Act allows states to create options for families with disabled children to buy into Medicaid while continuing to work. Parents would pay for Medicaid coverage on a sliding scale. Medicaid is critical to the well-being of children with multiple medical needs because it covers many services that these children need, including physical therapy and medical equipment, the senators said. Private health plans often are much more limited in what they cover. And many parents can’t afford needed services or multiple co-payments out-of-pocket.

Last year, the Finance Committee passed the bill on a voice vote, without controversy. The full Senate never considered the bill, although at the time the legislation had 74 Senate co-sponsors and more than 235 co-sponsors in the House (of a counterpart bill).

Grassley and Kennedy said the Family Opportunity Act is pro-work because it lets parents work without losing their children’s health coverage, pro-family because it encourages parents to work and build a better life for their children, and it’s pro-taxpayer because it means more parents continue to earn money, pay taxes and pay their own way for Medicaid coverage for their children.

“Parents want to provide the best they can for their children,” Grassley said. “Congress

should give states the flexibility to give families options without the federal government getting in the way.”

Medicaid is a medical assistance program jointly financed by the federal government and state governments for eligible low-income individuals. It also covers health care expenses for the needy elderly, the blind and the disabled receiving cash assistance under the Supplemental Security Income Program.

A bill summary of the Family Opportunity Act follows.

SUMMARY OF THE MAJOR PROVISIONS OF
THE GRASSLEY-KENNEDY FAMILY OPPORTUNITY ACT OF 2003
(also known as the “Dylan Lee James Act”)

PROBLEM

The National Health Interview Survey (NHIS) and current census data show that 8% of children in this country have significant disabilities, many of whom do not have access to critical health care services they need. In order for these families to get needed health services for their children, many are forced to stay impoverished, become impoverished, put their children in out of home placements, or simply give up custody of their children ---- so that their child can maintain eligibility for health coverage through Medicaid. Many employer health plans and a number of CHIP/SCHIP programs do not cover essential services that these children need to maintain and prevent deterioration of their health status. Medicaid can provide these comprehensive services.

In a recent survey of 20 states, families with special needs children report they are turning down jobs, turning down raises, turning down overtime, and are unable to save money for the future of their children and family ---- so that they can stay in the income bracket that qualifies their child for SSI and/or Medicaid.

Currently, less than 4% of the 850,000 children receiving Social Security benefits leave the Social Security rolls due to increased family income. However, many would if access to needed health services was available. More than half the States in this country are reporting increasing rates of families giving up custody of their children in order to secure needed health care services and supports.

The Family Opportunity Act of 2003 is intended to address the two greatest barriers preventing families from staying together and staying employed - (1) lack of access to appropriate services, and (2) lack of access to the advocacy and assistance services they need to help cut the “red tape” to meeting their children’s health care needs.

THE FAMILY OPPORTUNITY ACT OF 2003

Access to Health Care Coverage

Expanding Medicaid Coverage Options. A new optional eligibility category will allow states to expand Medicaid coverage to children with disabilities up to age 18, who would be eligible for SSI disability benefits but for their income or resources. This option builds on previous reforms including the provision enacted in the Balanced Budget Act of 1997 (BBA) and the Ticket to Work and Work Incentives Improvement Act of 1999.

These provisions permitted states to offer a Medicaid buy-in for disabled children who would be eligible for SSI disability benefits but for their income, who are in families earning up to 250% of poverty.

In order for a family to participate in the Medicaid buy-in for their disabled child or children, a state must require a parent to take employer-offered insurance within the following guidelines: (1) the employer offers family coverage under a group health plan, and (2) the employer contributes at least 50% of the total cost of the annual premium for the coverage.

If such coverage is attained by the family, the state is required to reduce the premium charged for the buy-in, in an amount that reasonably reflects the parent's premium contribution for private coverage for their child with a disability.

Participating states may charge premiums up to the full cost of the premium as long as that premium does not exceed 5% of the families income.

The state may waive payment of a premium in any case where the state determines that requiring a payment would create an undue hardship.

Option for States to Include Children Receiving Hospital Psychiatric Services in Home and Community -Based Waivers

States would be now permitted to include disabled children receiving inpatient psychiatric hospital services in the state's home and community-based service waiver program.

These children do not currently meet the eligibility criteria for services under the waiver because of the narrow definition of "institution".

Restoration of Medicaid Eligibility

Restores only the Medicaid eligibility for children meeting the "presumptive eligibility" requirements under SSI without having to wait until the "first day of the month following" the establishment of eligibility.

Access to Health Information and Resources

Establishing Family to Family Health Information Centers. The bill provides funds for establishing

health information centers to assist and support families of children with disabilities and special health care needs. These centers, staffed by both parents of children with special needs and professionals, would provide technical assistance and accurate information to other families on various health care programs and services available and appropriate for children with special needs, including identifying successful health delivery models. In addition, these centers would act as a resource to healthcare insurers, providers, and purchasers in developing ombudsman models for collaboration between families of children with special needs and health care professionals.